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### **The Ashley Rose Advancement in Research Award Established for Spina Bifida Research**

Washington, D.C. - Spina Bifida Association (SBA) and Spina Bifida Foundation (SBF) announce the establishment of the Ashley Rose Advancement in Research Award by Raymond and Linda Pitek (Massapequa, New York) through their foundation the Ashley Rose Foundation. This award becomes part of the group of fellowships offered through SBA's Young Investigator Research Program and is a true testament to the Pitek's dedication to promising research possibilities for Spina Bifida. The overall gift of \$250,000 will be allocated as an annual award of \$50,000 for five years.

"This charitable contribution comes at a time when researchers from multiple disciplines are on the cusp of discovering new treatments for Spina Bifida," says Cindy Brownstein, SBA's and SBF's President and Chief Executive Officer.

The Pitek's desire to unlock the mysteries around Spina Bifida began when they lost their newborn daughter Ashley Rose to severe complications from the birth defect on Valentine's Day 1996. This devastating loss left them eager to do something to honor their daughter and others who live with the challenges of Spina Bifida every day.

Throughout the years, the Piteks have worked with various support groups and SBA Chapters to build greater awareness about Spina Bifida in their area. Ultimately, they felt that investing in research was a step that they could take that could result in a huge impact for the future of those living with Spina Bifida. Inspired by the First World Congress on Spina Bifida Research and Care, an international gathering of Spina Bifida researchers and health care providers sponsored by SBA, as well as the development of SBA's Young Investigators Program, the Piteks established the Ashley Rose Advancement in Research Award. The award will become part of the Young Investigators' program which focuses on funding young scientists at an early point in their careers to encourage work in Spina Bifida.

In recognition of this tremendous gift, SBA and SBF have named the research session to be held at the Second World Congress on Spina Bifida Research and Care in honor of Ashley Rose. The meeting is slated for spring 2012.

Speaking at the recent Ashley Rose Charity Ball, Raymond Pitek illuminated this sentiment. "It can be tough at times because our story is filled with despair and a tremendous loss, but it is also filled with hope, faith, support, friendship, accomplishment and love."

For more information on the Ashley Rose Advancement in Research Award or the Young Investigators Research Program, please visit the SBA Research Center at [www.spinabifidassociation.org](http://www.spinabifidassociation.org).

Spina Bifida Association is the only national voluntary health agency working for people with Spina Bifida and their families through education, advocacy, research, and service. SBA was founded in 1973 to address the needs of the Spina Bifida community and today serves as the representative of 25 chapters serving more than 125 communities nationwide. The Association is the only national organization solely dedicated to advocating on behalf of the Spina Bifida community.

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